

Frequently Asked Questions:

Clinical Assessment

Q: What data should be captured for blood pressure if more than one method is used?

A: Enter the most accurate reading for that measurement.

Q: I understand there are forms for which an individual site license is required. How do I obtain these?

A: The following forms require individual site licenses prior to form collection.

1. **PDQ-39:** Fill out the license agreement available at <http://www.isis-innovation.com/outcomes/apply/index.htm>
2. **MDS-UPDRS:** Fill out the license agreement available at https://ssl47.pair.com/mds/publications/rating_scales/request_form.php
3. **Epworth Sleepiness Scale:** Fill out the license agreement available at <http://www.mapi-trust.org/services/questionnairelicensing/>

Biospecimen Collection

Q: If a site receives extra tubes or un-needed tubes sent from the NINDS Repository, can or should the site send them back?

A: No. Contact and they will adjust shipments in the future.

Q: Does DNA have to be collected on the first visit?

A: DNA can be collected at any visit, as this won't change over time. All other samples are longitudinal (ie, are expected to have changes over time). Therefore, DNA can be collected on any visit. This should be clarified in advance and coordinated with The NINDS Repository.

Q: For sites that have already enrolled subjects, when should existing data be entered into ProFORMS?

A: Once the site has access to the ProFORMS module, data from already enrolled subjects should be entered within **30 days**.

PDBP Consortium Questions

Q: Will a site be able to download data collected in ProFORMS?

A: This functionality will be available with the launch of the query tool at the end of May, 2013. NINDS program staff will be working with the PDBP sites to determine an initial set of reports that would be useful across sites.

Q: How can I access data and sample inventory information from our own site?

A: This function will be available with the query tool launch at the end of May, 2013

Q: How can I access data and sample inventory information from other sites?

A: Within the ProFoRMS database, as a member of the PDPB initiative, you will be able to access data and sample inventory information from other sites with the launch of the query tool at the end of May 2013.

PDBP DMR

Q: How do I get permission to ProFoRMS?

A: Permission to ProFoRMS must be granted by a system administrator. You can make the request by following the steps below:

1. Login to the PDBP DMR
2. Select Account Management
3. Select Request Additional Privileges
4. Check the ProFoRMS box
5. Click Request Privileges

Q: Why isn't my form saving?

A: Validation check errors are reported at the top of the screen upon save. Scroll up and address any issues listed, such as incomplete required fields or entry that is out of acceptable bounds; then try saving again.

Q: Why can't I edit a form?

A: Forms can only be edited by the person to whom they are assigned. To reassign a form, the owner must perform the following steps:

1. Click on the form you wish to reassign
2. Click Reassign
3. On the next screen, choose the username of the person to whom you wish to assign the form; then click Save to reassign the form

Q: Why can't I see the form I am attempting to collect data for?

A: Visit types are built into the system with any required and optional forms associated with that visit. Check that you have selected the correct visit type or contact the Operations Team at PDBP-OPS@mail.nih.gov or call 301-402-6781 for further assistance.

Q: What should I do if I can't see a button that I need to perform an activity?

A: Each user is assigned to a customized permission group. It is possible you don't have the permission to perform that action and the button is missing from your view. Contact the Operations Team at PDBP-OPS@mail.nih.gov or call 301-402-6781 to obtain a copy of the forms associated with each visit type.

Q: Why is the GUID tool not generating a GUID?

A: The GUID tool works best with Java Runtime Environment 7 or higher. Click [here](#) to check the version installed on your machine. If possible, please upgrade your system and try again.

Q: Can I create customized forms in the DMR?

A: The PDBP DMR is not currently configured to allow the entry of custom forms. However, this functionality may be available in the future.

Q: How can I try out the system without actually entering the data for my study?

A: There is a demo environment available for this exact purpose. Please contact the Operations Team at PDBP-OPS@mail.nih.gov or call 301-402-6781 to obtain access to this environment. Remember that data entered in the demo environment can be deleted at any time and cannot be transferred to your study.

Q: What should I do if I've locked a form and I need to change data on it?

A: Administrators are the only users with the ability to change locked data. Contact the Operations Team at PDBP-OPS@mail.nih.gov or call 301-402-6781 for further assistance.

Q: Will my password expire?

A: PDBP DMR passwords currently expire every 60 days according to NIH Security Policy. To prevent your account credentials from expiring, please reset your password at least once every 60 days. You cannot use a password that has been used within the past 25 changes.

To reset your password while your account is still active:

1. Login to the DMR
2. Select the Account Management module
3. Select Change Password from the left-hand navigation bar
4. Follow the steps listed

Q: What should I do if my password is already expired?

A: To reset your password after your credentials have expired:

1. Navigate to the DMR
2. Click on the "Forgot your password?" link near the top of the page
3. You will receive an email with a link to change your password.

Q: We are not currently a PDBP site or project. How can I collaborate with that group?

A: There is a one year embargo period beginning at the date of release of the notice of grant awards for the projects in the PDBP initiative. During this embargo period only PDPB investigators can access data across sites. Information about the individual PDBP projects is available at <http://PDBP.ninds.nih.gov>

Q. My question is not answered here. What should I do?

A. Please contact the PDBP DMR Operations team at PDBP-OPS@mail.nih.gov or call 301-402-6781 for further assistance. We will respond to your request within 24 hours.